Response to the National Disability Insurance Scheme Rules Discussion Paper.

Submitted on 1st March 2013 by Deborah Farrell on behalf of:

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SUBMISSION ON THE NATIONAL DISABILITY INSURANCE SCHEME RULES FROM MULTIPLE SCLEROSIS AUSTRALIA AND MOTOR NEURONE DISEASE AUSTRALIA

We appreciate the opportunity of commenting on the options set out in the consultation paper on the Rules for the NDIS, dated February 2013, in relation to the client groups our organisations support. We have responded to only those questions which have the most relevance for our client groups.

The Nature of Progressive Neurological Disease

Progressive neurological diseases (PND) are by definition incurable and the cause is often unknown. Most conditions follow a relatively predictable path, i.e. motor neurone disease is usually rapidly progressive while others generally relapse and remit and are harder to forecast, such as multiple sclerosis. The nervous system controls our movements, communication, sensations, thoughts, memory and emotional responses. Mood, behaviour, personality and judgment can all be disturbed. Therefore, the impact of these diseases can leave the individual physically, cognitively and socially disadvantaged and sufferers of PND have a high rate of social and financial disadvantage.

The age of onset and the timeframe of progression vary between individuals. Onset in young adulthood or middle-age can cause the early loss of employment. The attributes of these diseases threaten the sustainability of friendships and partnerships and many relationships fail, causing further isolation and increased reliance on social services. Therefore, the disease attributes must be taken into account when considering any intervention or policy regarding service delivery.

Individuals with PND often have frequent presentations to hospital emergency departments, crisis admissions with protracted hospitalisation, and are at high risk of inappropriately being placed in residential aged care. Timely early intervention, and specialist planning, assessment, and coordination of care, including a pro-active framework for decision-making, play vital roles in the prevention of these situations. The costs of time, duration of unnecessary supports, resourcing of avoidable hospital admissions, and cost associated with poor outcomes as a result of ill-informed/inadequate assessment, irrelevant/inappropriate choices, or a lack of support for the primary carer, all bear a financial and personal penalty.

Appropriately targeting financial and social supports early in the disease and before significant evidence of functional disability, can be expected to sustain individuals directly affected, and their family and social relationships, to a greater degree. In turn, the client retains all the benefits of informal care and the social enrichment of normal domestic life – a situation which, once lost, is hard to recapture as the disease progresses.
The different functions of the NDIS
Rule 1

Questions

- What sorts of general information and referral services should the Agency provide for people with disability who approach the NDIS?

and

- What guidance should the rules provide the Agency about how to support people in referring them to community or mainstream supports, or to other support systems?

We endorse that the support the Agency provides must be much more than information and referral, but ensure that a mechanism exists for connection to occur and a service is provided in an appropriate timeframe. Ensuring that people are connected is necessary for all people. However this is non-negotiable for people with complex social and health needs to reduce any increased risk of poor social and health outcomes due to hidden symptom, poor symptom and support management (e.g. fatigue, changes in memory, thinking and mood), resulting in depression, reduced, motivation and initiation. A proactive approach to co-ordination and follow through is imperative.

For these conditions, information must be individualised and personalised; this is a ‘light touch’ form of support which should be provided by specialist services using block funding. The Agency needs to take account of the lack of knowledge in generic services of the disease symptom management and disease trajectory of people with progressive neurological disease, such as multiple sclerosis and motor neurone disease. We emphasise that people who are transitioning out of other systems, such as hospital or community aged care, also require active support and liaison rather than simply information and referral.

The Agency workforce must have a good understanding of the roles and functions of other sectors and professional roles, and will need to develop pro-active working relationships with other portfolio areas; including health including primary care, rehabilitation and housing. It will also need to:

- Identify what is available and when, eg service directory
- Identify which is the most appropriate of what is available
- Be sure that these services are financially and quality robust
- Draw on resources and pre-existing relationships with services which have worked well for the person and their needs previously.

The Agency should not assume that there are adequate services or supports for people in other systems; and, if available, waiting periods frequently increase the risk for the person with a disability and their family. In addition, because the person with a disability and/or their family does not always know what they do not know, or need, it is important to ensure that the process for access to coordination/ service navigation is funded.
What guidance should the rules provide the Agency about funding of persons or organisations so that those persons or organisations may assist people with disability to realise their potential, and participate in, all areas of life?

It is important to value and support organisations with specialist, evidence-based practice and experience with specific conditions such as multiple sclerosis and motor neurone disease. We strongly support the block funding of specialist organisations to undertake the assessment, planning, and local area coordination functions for people with these conditions. These organisations have national and international links to research and evidence-based practice, and long-term experience in optimising outcomes for these groups.

Becoming a Participant

Age requirements
Rule 2

Question
- Should the rule also set out the types of information the Agency will need to establish that a person meets the age requirements?

We argue that motor neurone disease and multiple sclerosis are disabilities and not age related conditions. A new diagnosis over the age of 65 is not a high frequency occurrence, and should override the age limit rule.

Continuity of support
Rule 7

Question
- What factors should be considered in deciding whether the NDIS should provide continuity of support to someone who has been receiving assistance under other programs, but who would not otherwise be eligible for NDIS support?

The age limit of 65 is contentious in relation to the people we support, as outlined above. We note that at present in the Barwon launch site, there are people over the age of 65 using our services who receive disability support, and under the continuity of support and ‘no disadvantage’ test we emphasise that they should be NDIS eligible.

Continuity for those people with a disability under 65 receiving HACC support in the Barwon site, not accessing state disability funding, needs to be confirmed.
Disability requirements  
Rules 8-10

Questions

- What criteria/factors should be taken into account in determining whether a person meets the disability requirements?

For the people we support, both diagnosis and functionality must be taken into account in determining disability requirements. This is because the diagnosis is predictive of the course of the disease, and alerts to hidden symptoms which reduce functionality, such as fatigue. A strong research base exists which identifies the functional impacts resulting from dual diagnosis and multiple morbidities with these diseases, which is an important resource for the Agency.

It is important to take account of the social context of the person in identifying the impacts of their condition, their pre-existing commitments, relationships and supports, as well as the health-related aspects of their disability. Early intervention criteria also play a key role here; preventing a crisis from occurring is a key feature when considering eligibility.

- Should there be any guidelines on people being able to provide existing assessments to meet the disability requirements?

Yes. The development of guidelines to support utilisation of existing assessments will assist in the prevention of individuals telling their story repeatedly. For example, Disability Support Pension recipients should be able to use their Centrelink medical assessment records to validate diagnosis and functionality – there is no need to duplicate this type of assessment. In addition, the collation of information from various sources can provide greater clarity about the multiple contributing factors which inform the required supports. If the guidelines for providing existing assessments are kept simple, the process will be smoother; people will be more informed /empowered and can be more confident in self-assessing, making informed decisions and seeking supported decision-making where required.

The guidelines would be best tailored to the different disability cohorts.

- What should be considered in developing a rule on the types of persons who should conduct assessments?

It is evident that there are at least two stages in the assessment process; firstly the NDIS assessment ‘gateway’ and subsequently a more extensive process which draws together existing assessments and other information to determine reasonable and necessary supports. The ‘gateway’ process may or may not be able to be completed by a person with a neurodegenerative disease. We suggest that the Agency seeks the assistance of a specialist organisation as needed at this stage.
For the more extensive assessment, however, we believe that specialist service involvement is imperative to develop the appropriate personalised plan. It requires understanding of the disease process, the different forms of disability, the prognosis/trajectory of the disease and the likely anticipatory care and support needs. A collaborative approach is taken with the person to identify and support their capacity to participate in planning. Support options must then be determined by the person’s social context and their care plans.

A person centred approach which personalises information and provides the right information at the right time as needs change, is a key. Sound knowledge and relevant qualifications, training, and experience are all important, including lived experience.

**Early Intervention requirements**

**Rules 11-13**

**Questions**

- What criteria would be useful for determining the benefits of early intervention for mitigating or preventing deterioration in a person’s functional capacity to undertake activities such as mobility, self-care or self-management?

Early intervention criteria should support those strategies and interventions which:

  - Maintain day to day life roles and activities, tasks and functions for example; work, housing, and social participation.
  - Respond to symptoms and risks associated with social context, health needs, and carer burden eg young children at risk of becoming surrogate carers in one parent families where a parent has a neurodegenerative illness. Support to mitigate the long term mental and social impact for the children is a crucial early intervention.
  - Provide service coordination, information and education to improve access to early intervention benefits that occur at various points across the disease /life journey.
  - Focus on proactive therapies and exercises which build core muscle strength ahead of each phase of progressive decline: eg to delay the use of a walking aide; delay use of a wheelchair; and retain fitness for use of wheelchair.
  - We suggest that some episodic and/ or chronic conditions should automatically qualify for early intervention on the basis of diagnosis. These include Multiple Sclerosis, Parkinson’s Disease, and psychiatric disabilities.

- How can the support provided by families and other carers be made more sustainable by early intervention?

  - Early intervention targeted to individual circumstances will reduce carer burden and stress by minimising deterioration of the person’s condition,
enabling both the participant and their family to stay more connected to other social supports.

- Respite is an important early intervention for families.
- Education for carers, both about the condition and awareness of their own risk of depression and burnout (self-assessed), is an important early intervention approach to the sustainability of care. Education about the condition needs to include what is known about the progression of the disease. Planning pre-emptively for the next stage of support requirements has been shown to reduce carer injury and improve quality of life.
- Supports which allow the family to maintain employment and career development, to participate socially and economically themselves, are protective of the carer’s capacities over time. In particular, the quality of life of a carer spouse/partner must be protected and supported, to avoid relationship breakdown and separation.
- Accessible and accurate pathways to navigate services and supports to minimise stress and frustration for carers.
- Recognition of and response to the trauma caused by diagnosis, increasing impairment and high levels of depression which impact significantly on individuals’ and informal networks’ capacity to respond proactively.

**Participants’ Plans**  
**Reasonable and necessary supports**  
**Rules 14-18**

**Question**

- What methods or criteria should be used to determine those supports that would not be provided by the NDIS, based on the criteria set out in clauses 34 and 35 of the Bill?

**Comment:** The NDIS fundamentally needs to ensure the participant has a safe place to live appropriate to their condition, and services to keep them connected in the community. Costs should not be limited for supports that are ‘reasonable and necessary’ in regard to these requirements.

The NDIS should not cover aspirational aims that are optional by general community standards, at the expense of providing quality supports for the fundamentals of living and participating in society as well as possible.

**Management of Plans**  
**Rules 19-21**

**Questions**

- What criteria should be used by the Agency in deciding whether there is an unreasonable risk for the participant in self-managing funding?
Self-managed funding needs to be part of the discussion in assessment and planning i.e. some guiding questions to self-assess risk, and consider the importance from the individual’s perspective of fulfilling this function/task. For example, a person with multiple sclerosis may feel obliged to self-manage, but through a conversation may identify that they would really prefer not to because of fatigue as this fatigue impacts on mood, motivation and thinking and therefore decision making.

Risks associated with the condition need to be assessed. These include cognition and other symptoms, such as reduced initiation skills, memory, disorganised thinking, impulsiveness, and limited physical capacity to manage records, hard or soft copy.

A person’s current capability to manage their own finances is a good guide. The level of confidence and knowledge of budgeting to self-manage funds needs to be determined. For instance, someone may be bad at budgeting or figures; it may never have been important to them; or it hasn’t been their role within the family.

A prior history of poor financial management, such as gambling compulsion, is a contra-indication. Other indicators that the person may not manage funds well and place themselves at risk, include expending funds on unreasonable and non-essential expenses that do not relate to the plan.

The person’s relationship with significant others will be a guide as to whether he/she will be given appropriate support to self-manage funds, or whether there may be a risk of misuse of funds by others.

- What flexibility should a person have in making changes to their support arrangements without requiring a review of the plan?

Individual plans should indicate the level of flexibility anticipated. Flexibility should be based on the person’s social context and support, the level of disability, and complexity of health needs. Flexibility should be *assumed* when no change to the level of funds or support type is involved, for instance, a change of support provider. We emphasise the need for regular but not onerous scheduled plan reviews, and self-initiated reviews, to ensure ongoing alignment of the plan as a person’s capacities or circumstances change.

- What circumstances should trigger an automatic review of a person’s plan?
  - Circumstances which require an emergency or rapid response should trigger an automatic review. These include an increase in personal care requirements due to exacerbation in symptoms and functional impairment, an admission to hospital, or other crisis. The participant, their family/carer, service provider, or hospital should all be able to trigger the review of the plan.
If funding is not meeting the costs of planned services an automatic review should occur.

A change in the participant’s life circumstances not directly related to the condition, such as moving house, getting married/partner moving in, having a child, separation from partner, illness or death of carer/partner or significant change in their informal network should all trigger a review of the plan.

Concern from others that unmanaged mental health issues are impacting on capacity to self-manage or adhere to the planned goals, should be a trigger for automatic review.

Not spending funds in line with the plan, or expending half of allocated funds before the half way mark of annual funding, requires automatic review.

Criminal convictions or imprisonment are a trigger for automatic review.

- How can the concept ‘dignity of risk’ inform the development of these rules?

“Dignity of risk” is exercised when processes support the participant’s input regardless of their capacity at a given point in time. A person-centred approach will assist decision-making about appropriate levels of risk, including scope for testing/trialling new tasks or opportunities for the individual. Maximising lines of communication between participants, agency, carers and other stakeholders will also assist in gauging what dignity of risk should apply.

A report such as “Managing Risk in Community Services: a preliminary study of the impacts of risk management on Victorian clients and services’ is a helpful resource.¹

Supporting decision making
Rules 34-37

Questions

- What criteria should guide the decision to appoint a nominee?

Appointment of a nominee should be considered in the absence of adequate informal supports when there is a diagnosed or observed cognitive impairment and/or behavioural concern that is limiting independence and increasing vulnerability. This may include behavioural outbursts, police involvement, or demonstrated neglect of self or others such as children and personal environment. Inappropriate spending - too much, not enough or not timely – could also indicate that appointment of a nominee should be considered.

- Requirements and matters to consider in the appointment, suspension or cancellation of a nominee.

¹ Report on research funded by ARC linkage grant to Latrobe University with the Department of Human Services and the Office of the Public Advocate, 2006-2009
There needs to be a Charter which sets out expectations, responsibilities, safeguards, and measurable outcomes. The criteria need to include guidelines for determining competency and capacity. A potential nominee should declare any conflict of interest.

A nominee should be a person with a pre-existing relationship with the participant, and be well-informed about their condition. An application process will need to establish good character and capacity, including thorough screening. Requirements should include police checks and quality references which reflect trustworthiness; commitment and ability to act in the client's interest; and sound financial competency and capacity. In the case of a family member, there should be exemptions available when a history of a positive and capable relationship with the person can be demonstrated. A potential nominee should declare any conflict of interest.

Training, initial and ongoing, should be a requirement to ensure nominees are equipped for their task. In selecting a nominee it could be beneficial for the nominee to be a person who is able to have an enduring professional relationship with the person, who has a strong grasp of the fluctuations in the person’s condition/trajectory of disease, and can make tough calls.

There needs to be an audit process for picking up misuse of funds, and procedural guidelines for recovery of funds in these circumstances.

- Prescribing who must not be a nominee.

A nominee must not be a person who has previously been in conflict with the participant or who is not motivated by the participant's best interests.

- Other than duties to support decision making by the participant personally or to give appropriate weight to the participant's views, what additional duties should be prescribed to nominees?

It would be beneficial if the nominee were involved in some case management so they are aware of the full ramifications of any decisions. They should be part of a decision making team, fully aware of events and issues in the participant’s life and informed of options, choices and systems structures.